

# End-of-Life Treatment in Managed Care The Potential and the Peril

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The conduct of end-of-life health care in managed care organizations is important, mysterious, and interesting. It is important because some form of managed care is involved in most health care provided in the United States.1 Managed health care applies to many ways of organizing the provision and financing of health care, all of which have in common that they provide a specific set of health services to a defined group of people within a defined budget. This definition encompasses staff model health maintenance organizations, contractual relationships by which health care providers share the financial risk of providing health care to a health plan's members, and new forms of "integrated service networks." Health maintenance organizations (HMOs), preferred provider plans, and managed indemnity insurance cover 80% of the privately insured persons in the United States. Recent large-scale extensions of managed care to public programs of Medicare and Medicaid ensure the continued rapid growth of managed care. The raison d'être of managed care is to contain the growth of the cost of health care for groups of enrollees or to ensure that those costs do not exceed a predetermined budget.

Managed care plans cannot afford to ignore the cost of end-of-life care. About 10% of health care resources are used for the care of persons in their last year of life.23 This percentage is higher for Medicare, which meets the needs of older people who have more long-standing disease and who are more likely to die. It is correspondingly lower in non-Medicare managed care groups. Patterns of end-of-life health care for chronically ill persons differ dramatically from those of persons who become suddenly ill before death. The latter primarily require hospital and physician services; the former use more long-term care and home care. 4 Patterns of care also vary from region to region, according to demography, the habits and evolution of local health care systems, and regulatory issues. The organization of managed end-oflife care varies greatly; no single set of concerns or guidelines will apply equally well to all plans.

As yet, little has been published about the current practices or potential for large-scale management of

end-of-life care. 5.6 In addition, little has been published about the experiences of death and dying of patients in health plans. This may reflect the relative isolation of academic health centers from managed care. Some authors focus on the high cost of dying and on predicting which patients will have catastrophic costs. 7.8 There is no profile of the various courses of end-of-life care in various types of managed care organizations. The nature of hospice coverage in managed care contracts has not been systematically analyzed, except that it varies from none, to partial and disjointed, to comprehensive. Studies show that hospice, a form of managed end-of-life care, can be cost-effective and cost-saving, although the variety of institutional forms and changing patterns of use justify continued research. 9.12

Managed end-of-life health care is interesting because its different financial organizations, relationships between primary and specialized providers, and incentives on health care professionals offer areas of concern and opportunities for improving this form of health care. In one view, managed end-of-life care threatens patients and families with rationing of important emerging therapies, limited access to costly beneficial treatments, impersonal bureaucracies, and physicians whose advocacy to patients' interest is tempered by financial conflicts of interest and "loyalty" to the managed care organization.13 A brighter perspective is that the duty of managed care plans to provide comprehensive, longitudinal, and cost-effective care possibly offers a way out of the fragmented, bewildering, and uneven quality of the current health care system. It also decreases the incentive for health care professionals to overuse treatments, including those that clinicians, patients, and families might recognize as pointless, futile, or nonbeneficial in a setting of high-quality palliative care.

# Possible Benefits of Managed End-of-Life Care

As part of a comprehensive and longitudinal health care system that integrates primary, specialized, and ter-

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#### ABBREVIATIONS USED IN TEXT

AIDS = acquired immunodeficiency syndrome HMO = health maintenance organization

tiary care, managed care systems could improve the provision of end-of-life care.

### Integrated Health Care

Managed care provides a framework and incentives for effective collaboration between the diverse kinds of providers and health care services that are needed for end-of-life health care. Traditional fee-for-service reimbursement assumes that providers will properly integrate care with other providers. Too often this expectation is not met in end-of-life care. Clinicians may not understand how to create multidisciplinary care plans. Primary care providers may lose contact with patients with progressive chronic diseases who are referred to specialists. Fee-for-service reimbursement may create a disincentive for a specialist to improve care by referring a patient to a primary care professional, home care, or hospice program if such referred patients do not return to the specialist. Patients too often report being cared for by oncologists or primary care physicians who have provided expert specialty care but who are uninterested, inaccessible, or unskilled in the final stages of home or nursing home care for a now-dying person.

Managed end-of-life care offers the opportunity of access to a spectrum of health care services and professionals who have incentives and institutional means to work together. The institutional and financial integration of care changes incentives toward the use of primary care physicians, advanced practice nurses, specialists, and teams. It decreases perverse incentives against timely hospice referrals, has the potential of leading to more effective institutional means of communication between teams of providers, and may enable persons near the end of life to make choices that are centered on patients' total treatment plans rather than on the interests of separate or even competing generalists or specialized professionals. It should decrease the preoccupation with certifying that patients have less than six months to live before being referred to hospice that now causes hospice care to be delayed until just before death14 or to be underused for patients with non-cancer-related terminal illnesses. It will help patients and providers learn how to use the opportunities to improve care.

The shift to capitation-based, as opposed to servicebased, financing may change the political landscape regarding public policy for end-of-life health care. Health plans may be more inclined to support legislative alternatives to physician-controlled delivery systems for end-of-life care or to promote more effective coordination between health care providers—such as laws regarding out-of-hospital do-not-resuscitate orders that coordinate primary care orders with treatment by emergency medical systems.15

# Portable Records for End-of-Life Treatment Plans

Managed care organizations interact with and coordinate many kinds of professionals caring for patients. The current health care system loses the large majority of advance directives as patients are transferred from clinics or nursing homes to hospitals.16-20 Specialists or primary care providers may be unaware of the existence, location, or content of information about treatment or proxy preferences collected by other primary care professionals. Emerging electronic medical records offer the possibility of communicating the existence, location, or content of advance treatment or proxy plans or preferences to all professionals caring for a given patient. Such records, for example, could enable an emergency care provider to instantly become aware of the preferred proxy decision maker of an unconscious stranger arriving at an emergency department. The privacy and confidentiality issues with regard to electronic medical records must be addressed, however.21

# **Education About Planning** End-of-Life Care

The fact that managed care organizations care for a large number of persons in a community creates an opportunity for new forms of community-based planning education. They are required to do so by the Patient Self-Determination Act.<sup>22</sup> Although such education will have modest influence on healthy persons to plan, it can substantially increase the number of frail or seriously ill persons who complete advance planning.23-25 One managed care organization got 18.5% of its members to name a proxy by simply mailing a request and educational material.26 Another study found that an HMO's patients with the acquired immunodeficiency syndrome (AIDS) were less likely than AIDS patients at an academic center to have advance directives.<sup>27</sup>

#### Enhanced Accountability for Quality

Models for managed health care systems presume that organizations linking diverse hospitals, clinics, and community-based services will use large-scale data systems to monitor the processes and outcomes of health care. Such data will be used internally to monitor and improve the efficiency and quality of care. Various reform proposals would make this information available to patients (in the form of "report cards") to inform choices of health plans and to government and academic agencies for health planning and technology assessment. Minnesota, for example, has created a "data institute" to collect data about health plans' costs, quality, access, utilization, and benefit structures.

The prevalence and cost of end-of-life care make it a high priority for scrutiny using these data systems. Managed end-of-life care organizations are well situated to examine and improve the quality of longitudinal, multi-institutional end-of-life health care for both acutely and chronically ill persons in various delivery

models—nursing home, community-based, or hospital clinic-based primary care. Consumers and professionals could benefit from access to end-of-life report cards, for example, on pain control in patients with cancer and access to home care for all dying persons. Though it is doubtful that indicators of the quality of end-of-life care would, by themselves, influence patients to purchase a particular health plan, such indicators as part of an aggregate index of a plan's quality of health care could create a market incentive to improve end-of-life care.

#### Rationalizing Resource Allocation

Managed care organizations will undoubtedly seek to make end-of-life care more efficient and more rational. This will be difficult. Most authorities agree that advance planning to limit treatment, however beneficial from the standpoint of enhancing patient autonomy, will not reduce total health care costs.24 Even so, they may make end-of-life care better and more to patients' preferences. Given the inconsistent use of advance directives by providers, some suggest that managed care systems could support patients' treatment preferences by not reimbursing for treatment that is provided after a clearly stated refusal.15 One study of HMOs found that hospice care was cheaper than conventional medical care.29 Health plans will participate in an overdue discussion of the definitions of medically necessary and appropriate care and medical futility. It is possible that health plan contracts30 rather than laws will play a much larger role in how people articulate and "choose" the nature and limits of their legal claims on medical resources at the end of life.

# Possible Perils of Managed End-of-Life Care

#### Divided Loyalty

Managed care plans do not, as yet, have the same beneficent obligation to individual patients that physicians do. They are expected to balance the needs of ill persons with the needs of enrollees who are potentially ill and who have comparable claims on a plan's resources and with their own balance sheet. Plans specify the services they cover and attempt to define medically appropriate, medically necessary, and experimental treatment to accomplish this balancing. Such balancing will be done with end-of-life care as well. Highly publicized conflicts over decisions to not cover autologous bone marrow transplants dramatize the problematic ethical credibility of health plans as resource allocators.<sup>31</sup> People are deeply suspicious of the motivations of insurance companies in making decisions to allocate or ration resources<sup>32</sup> and should rightly suspect that persons making general resource allocations will decide differently than persons with a bedside perspective.<sup>33</sup> Minnesota health insurers have used a variety of ways to allocate and ration the use of hospice care, visiting nurse care, respite care, and spiritual and psychological counseling for end-of-life care. The morality of such decisions is not unique to end-of-life care, but end-of-life care promises to be a hot spot for the debate about these issues.

# Conflict of Interest

Health plans manipulate the credentialing of and incentives on health care professionals to meet financial goals. The credentialing affects the access of providers to reimbursement. The incentives may include bonuses for not providing or referring to costly services or contracts that attempt to limit what patients can be told about services that the plan does not wish to cover. The most troubling issue for end-of-life care in managed care is the possibility that clinicians are changed from being patients' advocates to having a personal stake in withholding treatment that would be in the patients' interests. Such conflicts destroy the trust that is the necessary foundation for good end-of-life care. The possibility that they might involve hospice providers who perform gatekeeping to hospital services or costly medicines like zidovudine (AZT) for persons with AIDS<sup>34</sup> properly causes great concern.

#### Devaluing Persons at the End of Life

Fee-for-service incentives create an incentive to care for and treat persons at the end of life even though many providers or society itself does not greatly value these persons or meeting their needs. Managed care poses potential threats to vulnerable, undervalued people who are ill suited to advocate for their own interests. First, in managed care budgets, the treatment of dying persons is a cost, not a revenue, except to the degree that choices for less expensive palliative care offset the greater costs of hospital or high-tech treatment. 9,35-37 Prolonged laborand technology-intensive palliative care is expensive even if it does lead to a better-quality death. Managed care budgeting has the dangerous potential of aligning the economic incentives for treating dying or chronically ill persons with social prejudices against them. The worst possibility would be a managed care system that limits access to both hospital and nursing home care in favor of home care and then provides inadequate community-based home care as well.38 Second, the corporate culture of large managed care organizations may adversely affect the possibility of humanistic alternatives to institutionally managed end-of-life care. 39,40 Though few would argue against technologies that improve the quality of end-of-life care, the hospice movement has renewed such care by its example of personal, small-scale, and charismatic institutions. The bureaucratic consolidation of end-of-life care in large managed care systems' should not foreclose this kind of humane and prophetic challenge to health care professionals or this kind of hope for dying persons and their loved ones.

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